



**Testimony of**

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**Hearing on**

**Federal Health Programs and Those Who Cannot Care for Themselves:**

**What Are Their Rights, and Our Responsibilities?**

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Chairman Souder, Representative Cummings, distinguished members of the Subcommittee, thank you for inviting me here today to discuss the role of Medicare, Medicaid and advance directives for those who cannot care for themselves. We are committed to ensuring that Medicare and Medicaid beneficiaries receive appropriate care tailored to their own needs and that they understand their rights and options in all care settings. As the Subcommittee undertakes an examination of policies regarding the status and legal rights of incapacitated individuals, I appreciate the opportunity to provide an overview of the role of the Medicare and Medicaid programs, as well as other programs within the jurisdiction of the U.S. Department of Health and Human Services. Medicare and Medicaid both play an important role in financing care for patients who may need to make choices about the types of health care they want. Medicare and Medicaid serve to protect the health of individuals at every stage of their lives, including when they cannot speak for themselves. However, decisions about health care itself are not made by Medicare and Medicaid. Such decisions are made by individuals and their families in consultation with their physicians.

Medicare provides coverage for beneficiaries in hospitals, skilled nursing facilities (SNFs), home health care, and hospice care, as well as physician and outpatient services. Medicare will cover only medically necessary diagnostic and treatment services. Medicare does not pay for purely maintenance or custodial services for persons not needing medical care. For Medicaid, states may offer a variety of acute and post-acute care services for eligible individuals. Additionally, Medicaid may pay for custodial services in a variety of settings.

The Patient Self Determination Act of 1990 requires that all adult patients in all covered settings be informed of their rights under state law to accept or refuse medical treatment and the right to formulate an advance directive. According to section 1866(f) of the Social Security Act, an advance directive is "a written instruction, such as a living will or durable power of attorney for health care, recognized under State law, relating to the provision of health care when the individual is incapacitated." This also includes "do not resuscitate" (DNR) orders. Compliance with section 1866(f) is a condition of participation under the Medicare program for hospitals, hospices, skilled nursing

facilities, and home health agencies. Medicare Advantage plans and Medicaid managed care organizations must also comply with identical requirements.

### **Enrollment and Spending under Medicare and Medicaid**

Over 42 million Americans receive their health coverage through Medicare including 6.5 million beneficiaries below the age of 65 who have disabilities and about 5.1 million over the age of 65 who have limitations in three or more activities of daily living. Eight million individuals with disabilities and 4.5 million senior citizens rely on Medicaid for their health insurance and long-term care and supportive services. Many of these beneficiaries may become incapacitated and incapable of making health care decisions for themselves. Anyone, at any age, may encounter a medical crisis that may temporarily or permanently diminish his or her ability to make personal health care decisions.

Medicare and Medicaid beneficiaries receive services in a variety of settings. Medicare spent \$34 billion in 2002 on post-acute care for 205,000 beneficiaries in skilled nursing facilities and \$42 billion on 1.4 million full benefit dual-eligible beneficiaries in skilled nursing facilities. In 2004 the federal government and states spent \$46.5 billion for approximately 1.8 million Medicaid-only beneficiaries in nursing facilities and an additional \$12.1 billion on approximately 117,000 beneficiaries in intermediate care facilities for individuals with mental retardation.

In FY 2002, approximately 110,000 Medicaid enrollees received hospice care and in FY 2003, more than 640,000 Medicare beneficiaries received hospice care. Medicaid spending on hospice was approximately \$700 million in FY 2002 and Medicare spending on hospice was approximately \$7.2 billion in 2004. Medicare spending on hospice has grown from \$1.9 billion in 1995 to an estimated \$7.2 billion in 2004.

In 2000, approximately 4 million individuals annually received care in hospital intensive care or coronary care units, and it is estimated that more than half of this population were receiving either Medicare or Medicaid benefits, or both.

### **Facilities Offering Care for Those Who Cannot Care for Themselves**

The federal Medicare and federal-state Medicaid programs cover care in a range of settings for those who cannot care for themselves. For eligible Medicare beneficiaries this includes skilled nursing facilities (SNFs) for extended care after a hospital stay and some health services at home. Under Medicaid states cover some long-term care services in nursing facilities if a beneficiary meets applicable state and federal eligibility requirements. While states are required to provide home health services for persons eligible for nursing facility services, many also have obtained waivers to make home and community-based services available to individuals who would otherwise qualify for Medicaid only if they were in an institutional setting. States also have the option to provide services through intermediate care facilities for the mentally retarded for those who are eligible.

In addition, for individuals with a terminal illness, both Medicare and Medicaid cover hospice services in facility-based settings including nursing facilities, hospitals, or other facilities and in patients' homes. Hospice covers a broad range of medical, personal assistance, and social services with the goal of keeping the patient comfortable and pain-free and supporting the family. Hospice care was added as a benefit under the Medicare program in 1983 and as an optional benefit under Medicaid in 1985. The number of beneficiaries electing hospice care, and the number of agencies offering such services, has grown steadily ever since.

To be eligible for hospice care, an individual's physician and the hospice medical director must certify that the individual is terminally ill, with approximately six months or less to live if their illness runs its normal course. Beneficiaries must sign a statement indicating that they understand that they are choosing palliative hospice care instead of routine, curative Medicare covered benefits for their terminal illness. The Medicare and Medicaid programs recognize that terminal illnesses do not have entirely predictable courses; therefore, if the patient surpasses the initial six-month prognosis, the beneficiary may remain eligible for hospice if the individual's physician and hospice medical director recertify that the patient has a life expectancy of six months or less.

CMS develops Conditions of Participation (CoPs) and Conditions for Coverage (CfCs) that health care organizations must meet to participate in the Medicare and Medicaid programs. These standards are used to improve quality and protect the health and safety of beneficiaries. CMS also ensures that the standards of accrediting organizations recognized by CMS (through a process called "deeming") meet or exceed Medicare standards. CoPs vary by facility-type (e.g. nursing facilities and skilled nursing facilities) and include a vast number of conditions related to, for example, patient rights, medical staff, skilled nursing and rehabilitation services, and food and dietetic services. However, one CoP that is applicable to most facilities is the requirement regarding advance directives.

### **Advance Directives**

It is important for individuals to know how advance directives can ensure that they receive the kind of care they choose. Living wills specify individuals' desired medical decisions if they are incapacitated and cannot speak for themselves. Proxy appointments and durable powers of attorney for health care designate a third party to make medical decisions if an individual becomes incapacitated.

Advance directives address both treatments individuals do and do not want. For example, an individual may prefer that health care providers perform all possible life-prolonging treatments. Conversely, a person may elect to receive non-curative care. Therefore, if an individual has specific treatment preferences, they would be able to document them in an advance directive.

### *Provider Requirements*

Sections 1866(a)(1)(Q) and 1866(f) of the Social Security Act, which codify the Patient Self Determination Act of 1990, mandate that most institutions receiving Medicare and Medicaid funding inform all adult patients – regardless of whether they are entitled to Medicare or Medicaid – of their right to accept or refuse medical treatment through an advance directive. Most health care institutions must maintain written policies and procedures concerning advance directives with respect to all adult individuals receiving

medical care, and are required to provide written information to such individuals concerning the following.

- An individual's rights under state law (whether statutory or recognized by the courts of the state) to make decisions concerning such medical care
- The written policies of the provider or organization respecting the implementation of such rights, including a clear and precise statement of limitation if the provider cannot implement an advance directive on the basis of conscience

In addition, providers must document in the individual's medical record whether or not the individual has executed an advance directive and may not discriminate in the provision of care to an individual based on the existence of an advance directive. Providers must also comply with state law regarding advance directives, and provide for education of the staff and communities on issues concerning advance directives.

### **Other Types of Beneficiary Protections**

In addition to Medicare and Medicaid, other government programs and services are available to families addressing health care issues for vulnerable individuals, including federal, state, and local government partners that include ombudsmen, protection and advocacy groups, adult protective services, and child protective services. These include the Health Resources and Services Administration programs that provide services for persons with traumatic brain injury. More specifically, the Administration on Aging (AoA) has a strong commitment to protecting the rights of seniors and helping them when they need to make end-of-life care decisions.

### *Survey and Certification*

The Survey and Certification Group in CMS' Center for Medicaid and State Operations is responsible for overseeing the programs established to monitor quality of care and ensure beneficiary protections within the Medicare and Medicaid programs; for ensuring that corrective action is taken when problems are found; and for ensuring that beneficiaries receive quality care in a safe environment.

CMS' requirement that providers initially meet eligibility qualifications and recertify to ensure continued compliance is intended to protect beneficiaries. Furthermore, CMS conducts complaint investigations of facilities in response to beneficiary concerns about care. As an example, approximately 6,000 Federal and state surveyors conducted on-site reviews of nursing facilities. On average, skilled nursing facilities are surveyed every 12 months, home health every three years, and hospice every six years. In addition to the role of the Survey and Certification Group, CMS provides beneficiaries with online tools, including Nursing Facility Compare, Hospital Compare, and Home Health Compare so that they and their caregivers can make informed decisions about long-term and other care services.

#### *Administration on Aging (AoA) Programs to Prevent Elder Abuse*

AoA has a range of programs available that allow millions of seniors to age in place with dignity. AoA also supports a range of activities at the state and local level designed to prevent elder fraud and abuse and inform seniors of their rights. These activities include training law enforcement officers and medical professionals in how to recognize and respond to elder abuse cases, conducting public awareness and education campaigns, and creating statewide and local elder abuse prevention coalitions and multi-disciplinary teams.

#### *National Family Caregiver Support Program (NFCSP)*

The enactment of the Older Americans Act Amendments of 2000 established an important new program, the National Family Caregiver Support Program (NFCSP). The program was developed by AoA and was modeled in large part after successful state programs (i.e. California, New Jersey, Wisconsin, and Pennsylvania). The program calls for all states, working in partnership with local area agencies on aging and faith- and community-based service providers and tribes, to offer five direct services that best meet the range of caregivers' needs, including:

- Information to caregivers about available services;
- Assistance to caregivers in gaining access to supportive services;
- Individual counseling, organization of support groups, and caregiver training to assist caregivers in making decisions and solving problems relating to their roles;

- Respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and
- Supplemental services, on a limited basis, to complement the care provided by caregivers.

AoA developed a fact sheet that explains the services provided by hospices and how to find information on the financial, legal, and after-death responsibilities that families must address.

### *Ombudsman Program*

The AoA also administers an ombudsman program under which local ombudsmen work on behalf of residents in hundreds of communities throughout the country. Long-term care ombudsmen are advocates for residents of nursing facilities, board and care homes, assisted living facilities and similar adult care facilities. Since the program began 30 years ago, thousands of paid and volunteer ombudsmen have made a dramatic difference in the lives of long-term care residents. Ombudsmen advocate on behalf of individuals and groups of residents, provide information to residents and their families about the long-term care system, and work to effect systems changes on a local, state and national level. They provide an on-going presence in long-term care facilities, monitoring care and conditions and providing a voice for those who are unable to speak for themselves.

AoA also serves as a resource for those who need help in making decisions regarding long-term care. Information on hospice, living wills, advanced directives, palliative care, advocacy, and professional information is provided on the AoA's website ([www.aoa.gov](http://www.aoa.gov)).

### *Advocacy and Support Organizations*

A number of organizations are dedicated to helping people address end-of-life issues. For example, AoA has worked closely with the National Hospice and Palliative Care Organization to provide information on hospice and palliative care services. Such organizations work to improve the quality of services available, as well as provide information and resources on related issues, such as advanced directives and living wills.

Nearly 1,000 AoA-funded legal providers help seniors to obtain medical and financial powers of attorney, living wills, and advance directives (combination of a medical power of attorney and a living will). These legal tools prevent unnecessary guardianships and help seniors to make informed end-of-life decisions. AoA funded the American Bar Association Commission on Law and Aging to create English and Spanish versions of the guide “Health and Financial Decisions: Legal Tools for Preserving Your Personal Autonomy.”

### **Conclusion**

We are committed to ensuring that vulnerable beneficiaries receive appropriate care through Medicare and Medicaid that is tailored to their needs and that they understand their rights and options. Mr. Chairman, as you can see, a variety of protections are in place in Medicare, Medicaid, and beyond these programs to ensure that beneficiaries receive appropriate health care. I thank you for holding this hearing, and I am happy to answer your questions.